DOCUMENT RESUME

ED 117 908 EC 081 331

TITLE	Avenues to Change: A Coordinator's Guide for Training Citizen Advocates.
INSTITUTION	National Association for Retarded Citizens, Arlington, Tex.
SPONS AGENCY	Bureau of Education for the Handicapped (DHEW/OE), Washington, D.C.; National Inst. of Mental Health (DHEW), Rockville, Md.; Rehabilitation Services Administration (DHEW), Washington, D.C.
PUB DATE	Sep 75
GRANT	OEG-0-72-5311
NOTE	119p.; For related information, see EC 081 332 and EC 081 114-117
EDRS PRICE	MF-$0.83 HC-$6.01 Plus Postage
DESCRIPTORS	*Child Advocacy; Community Resources; Exceptional Child Services; *Guidelines; Inservice Education; *Institutes (Training Programs); *Mentally Handicapped; Organizations (Groups); *Program Development
IDENTIFIERS	Citizen Advocacy; National Association for Retarded Citizens

ABSTRACT

Intended for coordinators of citizen advocacy programs for mentally retarded persons, the guidelines developed by the Association for Retarded Citizens provide an overview of training sequence and procedures, suggestions for two training sessions, and topics for followup activities. Listed are training objectives (including defining the role of citizen advocates), and analyzed are the steps involved in screening, training, matching the advocate to the mentally retarded protege, and providing followup inservice training. Descriptions of two sample training sessions include information on such topics as a basic orientation to mental retardation, the normalization principle, community resources, and resource materials for the citizen advocate. Objectives, references, approaches, and materials are suggested for followup training on such aspects as current trends in legislation and poverty and retardation. (CL)

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A COORDINATOR'S GUIDE FOR TRAINING CITIZEN ADVOCATES

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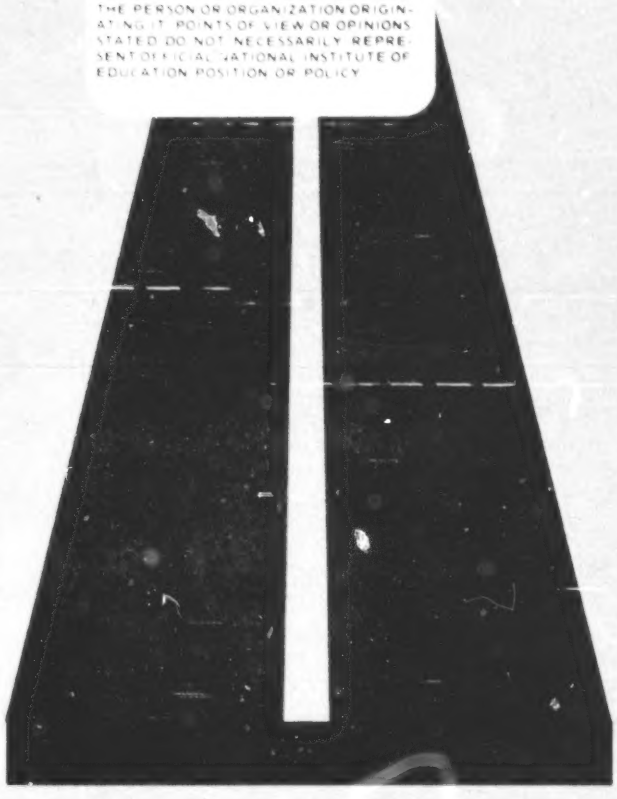

Avenues To Change

2

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EC081331

A COORDINATOR'S GUIDE

FOR TRAINING CITIZEN ADVOCATES

This guide was developed in conjunction with the NARC Project, A National Citizen Advocacy Model for Mentally Retarded Children, Grant #OEG-0-72-5311, which is supported jointly by the Bureau of Education for the Handicapped, National Institute of Mental Health, and Rehabilitation Services Administration of the United States Department of Health, Education, and Welfare.

September, 1975

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SECTION I

TRAINING SEQUENCE AND PROCEDURES

PREFACE

The Citizen Advocacy approach has rapidly gained widespread acceptance as a viable method for ensuring that mentally retarded children and adults are receiving needed services, enjoying their legal and human rights, and experiencing personal support and friendship. The effectiveness of this approach is dependent upon the knowledgeable participation of the volunteer advocate through instruction and training from the local Citizen Advocacy Office. The training of citizen advocates is an essential feature of this new volunteer program and very crucial to the competency and effectivensss of the the advocate.

The major purpose of this guide is to assist local Citizen Advocacy staff in their efforts to adequately train advocates. This guide supplements Book III of NARC's Avenues To Change series which also provides information for citizen advocates. Another very important purpose is to appropriately emphasize both instrumental and expressive advocacy roles during the training process.

In an effort to facilitate the understanding and use of this guide, the contents are divided into four major sections: (1) specific information on the training sequence and procedures; (2) detailed guidelines for conducting a basic and advanced training program; (3) suggested topics for monthly in-service training programs; and (4) resource materials which are keyed to each topic in the training programs. There are also master schedules preceding the basic and advanced training

programs (pages 11 and 72) to assist the instructor in maintaining necessary time frames for each topic area.

The second section on conducting two formal training sessions is written as a narrative outline to cue the trainer to important ideas to share with new advocates. The structure of these sessions allows for spontaneous and informal interaction. It is recommended that the trainer study this guide, research additional information in any unfamiliar topic areas with the aid of suggested resource materials, and then use the outlines as a guide during actual training sessions.

The initial or basic training sessions help the advocate to acquire a basic understanding of mental retardation, the concept of Citizen Advocacy, and the roles and obligations of the advocate. This basic training should be provided for all prospective advocates prior to their being matched with a protege. The follow-up training sessions may precede or follow matching, since they focus on information which will increase the effectiveness of the advocate.

The contents of the guide are based on actual Citizen Advocacy training programs conducted by several local programs. Each topic in the training program is highly relevant to the preparation of volunteers for roles in the Citizen Advocacy approach.

NARC's Child Advocacy Project extends its thanks to: Mrs. Leola Novak, Capital ARC, Lincoln, Nebraska; Ms. Betty Hallgren, Denver ARC, Denver, Colorado; Ms. Helen Zauha, formerly of the

Greater Omaha ARC, Omaha, Nebraska; and, of course, to Dr. Wolf Wolfensberger, with whom the concept of Citizen Advocacy originated.

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INTRODUCTION: AN OVERVIEW OF TRAINING CITIZEN ADVOCATES

The formal preparation of prospective advocates for their roles has been referred to as training by some people and as an orientation by others. Definitions of these two processes are as follows:

> "Train:...3: To subject to certain action, exercises, etc., in order to bring to a desired condition 4: To guide or control in mental, moral, etc., development of; bring up; rear 5: To instruct so as to make proficient or qualified.
>
> "Orient:...3: To adjust with relation to facts or principles, correct 4: To adjust or adapt to a particular situation..."
>
> -Webster

The development of effective citizen advocates requires more than orientation. The training of citizen advocates should not only form attitudes, but should also provide the sound background that will launch them into effective advocacy activities.

This training guide, drawn from the practical knowledge of several experienced coordinators in the field, is compiled to ensure that the citizen advocates in every program begin their new roles with confidence, assurance, and some expertise.

TRAINING OBJECTIVES

The major purposes of the training program are to:

1) Shape citizen advocates' attitudes so that they will be able to accept their proteges as individuals;
2) Instill realistic expectations in terms of what citizen advocates can actually accomplish and at what rate of speed;
3) Help citizen advocates learn to anticipate growth and change and not to underestimate their proteges;
4) Explain to citizen advocates the continuum and flexibility of advocacy roles and how these roles alter to meet the changing needs of their proteges;
5) Define for the citizen advocates what their basic responsibilities will be;
6) Relay practical information of a general nature which may be useful to every citizen advocate;
7) Reassure citizen advocates, giving them a sense of greater competence to deal with their new roles by having been trained;
8) Assist the coordinator in getting better acquainted with the citizen advocates and their potentials; and
9) Reassure the proteges' families and friends, professionals in the field of mental retardation, and the general community that citizen advocates are trained to fulfill their roles.

TRAINING STEPS

The training of a citizen advocate actually begins with the volunteer's first exposure to the concept of Citizen Advocacy. With each step in the process of becoming a citizen advocate, the volunteer develops greater awareness of what the program is, where it came from, what it tries to accomplish, who the people are that it serves, and what is expected of an advocate.

The sequence of events for becoming a citizen advocate can be viewed as follows:

Training/Orientation

screening

1) Volunteer's first exposure to the Citizen Advocacy concept.

2) Initial interview

3) Application to become a citizen advocate

training

4) Group training sessions

5) Individual study; optional tours or visits

matching

6) Informal match; first encounter with protege

7) Formal match

8) Second interview

9) Intensive follow-up (3-6 months)

in-service training

10) Monthly advocate group meetings (follow-up training sessions)

11) Semi-annual group functions for advocates and proteges.

This sequence is not totally rigid. Each coordinator's unique personality and individual style will dictate to a large extent the means by which a volunteer becomes a

citizen advocate. There may be additional steps or fewer; the sequence may vary considerably. The degree of structure used in achieving these steps may also vary. Only the underlying theme is essential: to train a volunteer to be a competent, qualified citizen advocate, and to give the citizen advocate the self-confidence required in order to undertake this role effectively. <u>However, it is essential for success that formal group training sessions be unfailingly included</u>.

It is step #4 (group training sessions) that this guide deals with in depth.

<u>DISCUSSION OF TRAINING STEPS</u>

1) <u>Initial Contact</u>. The amount of information the volunteer gleans from his initial exposure to the Citizen Advocacy concept will vary greatly. A radio spot, an ad in the paper or a brochure provides brief information to arouse the potential volunteer's curiosity. A feature article, a television program or a speech by the coordinator will give the volunteer a more comprehensive understanding of Citizen Advocacy. An individual drawn to the program by the Citizen Advocacy experience of a close friend will probably be your best-informed volunteer.
2) <u>Initial Interview</u>. It is important at this time to consider the volunteer's familiarity with Citizen

Advocacy. Although the initial interview is designed primarily as a structured screening procedure, the volunteer is also scrutinizing the coordinator, the program and the responsibilities involved in becoming a citizen advocate. The coordinator should give as much information as possible at this stage about the role of a citizen advocate and the commitment involved in an intensive one-to-one relationship. Let the prospective volunteer know exactly what steps will be involved in becoming a citizen advocate and what types of back-up and support are available to advocates.

3) Application. Filling out and sending in an application may not appear to be a part of the training process, but in many ways it is. The volunteer has been deciding whether or not to become a citizen advocate. Filling out and signing the application implies arrival at a decision; it is a statement of commitment that is as significant to the volunteer as it is to the coordinator. Furthermore, questions on the application relating to the general description of the potential protege (age, sex, degree and nature of disabilities) and why the volunteer wishes to be an advocate force an examination of personal motives and needs. If the prospective advocate is accepted into the program, a copy of Avenues To Change: Effective Advocacy (Book III) should be provided and studied prior to the formal

group training sessions.

4) Group Training Sessions. These group activities are the volunteers' major training sessions. This is the point at which the volunteers receive formal preparation for becoming citizen advocates. They are provided with concrete information, encouraged to investigate their own expectations and attitudes, and share a learning experience with each other. They experience participation in a movement and realize that they will not be functioning as isolated individuals.

The coordinator should carefully consider and evaluate the degree of awareness of each of the recently trained advocates. The following are some points to consider following the group training sessions. Did the volunteer:

--Express confusion over the principles and goals of Citizen Advocacy by his questions and comments?

--Fail to contribute to group discussions and interchanges of ideas?

--Seem to be slow in picking up the information dealt with at the training session?

--Seem to be overly aggressive and/or abrasive in attitude or speech?

--Appear to be immature?

If any of the first three points apply to a new citizen advocate, some additional one-to-one consultation between coordinator and advocate, geared to the advocate's own pace, may be in order. If the advocate still displays some lack of understanding, or if the

fourth or fifth points apply, the coordinator may consider an apprenticeship of the new advocate to a more experienced advocate before matching with a protege. The length of such an apprenticeship must be individually determined, of course, depending on feedback from both new and experienced advocates, the protege involved, the coordinator's own perceptions and possibly the observations of the protege's family or close associates (e.g., teacher, social worker, and peers).

5) Individual Study. The citizen advocate operates on personal initiative during this stage and can obtain whatever additional information may be necessary. In addition to studying written materials, the volunteer may feel a need to develop a better understanding of available services for mentally retarded people by visiting local facilities (e.g., workshops, schools, and public institutions). If this is the case, the coordinator may facilitate these visits by making appropriate arrangements. However, it is important that any such tours or visits follow the attitude-shaping training sessions.

6) Informal Match/First Encounter. During this critical step, the advocate comes face-to-face with the potential protege. The coordinator must try to make both people comfortable enough so that they can learn as much as possible about one another during this initial encounter

before either party makes a firm commitment.

7) Formal Match. The coordinator ascertains from personal or telephone contact that the protege, his or her family if they are involved, and the advocate have decided to accept each other and to continue their relationship.

8) Second Interview. The advocate needs to learn something of the protege's medical needs or problems, lifestyle, interests, and close associates. If special rules and regulations exist concerning the protege's living arrangements (e.g., house rules of natural, foster, or small group homes, or regulations of an institution), the citizen advocate should also receive this information. The advocate should be informed as to what kind and degree of preparation the protege has had for participating in the program, and what the protege's expectations are regarding having a new friend.

At the next meeting of the advocate and protege, the citizen advocate should share basic information about himself with the protege, including phone number(s), work schedule, and family responsibilities.

8) Intensive Follow-Along (3-6 months). The citizen advocate usually has many questions, concerns and doubts during this period. Next to the group sessions, this training period is the most important for the citizen advocate. The coordinator must anticipate problems and frustrations, help the volunteer learn to cope

with awkward situations, and assist the advocate in learning to trust his or her own judgment.

During this time, the coordinator should assist the advocate in meeting with other people who are active in the protege's life for the purpose of mutual sharing and guidance. A group conference may even be in order. The advocate will want to become acquainted and maintain contact with house or cottage parents, teachers, therapists, employers, social workers, medical workers, program directors, etc.

9) Monthly Advocate Group Meetings. On-going in-service training should be available to all advocates. From time to time each advocate needs to get "re-charged" by the commitment and caring of other citizen advocates. (Suggestion: the citizen advocates may wish to alternate times of these monthly meetings to give as many advocates an opportunity to attend as possible.) Refer to the section on "Monthly In-service Training Sessions for Advocates", pp. 93-101 in this guide.

10) Semi-Annual Group Function For Advocates and Proteges. This also represents in-service training, no matter how social the event! It is a refresher course in that participation in a movement feeling. The coordinator might enlist the organizational expertise of the local Youth ARC, church groups, college clubs, or Voluntary Action Center volunteers for planning such an event.

FIRST TRAINING SESSION

Time: Approximately 2-1/2 - 3 hours.

Attendance: The size of the group for training should range from four to ten volunteers. The coordinator might first call to determine what day and time would be convenient for those who will be attending, then send out written notices which also announce the date and time of the second training session, and follow-up with a call the day before the event.

If possible, there should be a second presentor in addition to the coordinator in order to add variety and increase interest. An assistant coordinator, state coordinator, or Advisory Committee member may be willing to address certain topics.

Materials: Basic equipment and materials for the training session include:

1) One large chalkboard
2) Chalk and eraser
3) One 35 mm. carousel slide projector
4) One movie screen
5) Normalization Exercise cards for Part IV (see p. 58)
6) Tables and chairs for the volunteers being trained
7) Pads and pencils
8) Refreshments
9) Ashtrays

TIMETABLE FOR FIRST TRAINING SESSION

This schedule indicates the maximum amounts of time which may be devoted to each activity in the first training session. Reference materials for the instructor are also listed.

Time		Activity	Reference Materials
20 min.	Part I:	Stereotyped Attitudes Toward Mentally Retarded Persons Group Work: "Stereotype Exercise and Discussion"	Attitudes
20 min.	Part II:	A Basic Orientation to Mental Retardation Lecture: "An Overview of the Nature and Causes of Mental Retardation"	Avenues To Change, Book III Residential Programming for Mentally Retarded Persons Book I Prevention Handbook
35 min.	Part III:	History and Practices Concerning Mentally Retarded Persons	Avenues To Change, Book III Changing Patterns in Residential Services for the Mentally Retarded
-25 min.		Slide Presentation: "History of Mental Retardation"	
-10 min.		Lecture: "Common Models and The Changing Thrust"	

Time	Activity	Reference Materials
15 min.	BREAK	
50 min.	Part IV: The Normalization Principle	Changing Patterns in Residential Services for the Mentally Retarded Avenues To Change, Books I & III The Principle of Normalization in Human Services
-5 min.	Introduction: "Normalization"	
-15 min.	Slide Presentation: "An Overview of the Normalization Principle"	
30 min.	Group Work: "Normalization Exercise"	
10 min.	Part V: The Developmental Model	Avenues To Change, Book III
	Lecture: "Underlying Assumptions and Goals of the Developmental Model" and "The Relationship between the Developmental Model and the Normalization Principle"	
20 min.	Part IV: A Final Word on Risk and Courage	The Dignity of Risk
	Group Discussion: "Risk and Courage"	

TOTAL TIME: 2 hours and 50 minutes

PART I: STEREOTYPED ATTITUDES TOWARD MENTALLY RETARDED PERSONS

Steps For The Instructor:

step one - state the purposes of the activity by referring to the objectives for Part I: STEREOTYPE EXERCISE AND DISCUSSION.

step two - conduct the activity according to the outline provided under STEREOTYPE EXERCISE AND DISCUSSION, pp. 14-17.

step three - answer questions relative to the discussion on stereotyping.

OBJECTIVES FOR PART I: STEREOTYPED ATTITUDES TOWARD MENTALLY RETARDED PERSONS

The purposes of this activity are to:

1) "Break the ice" and initiate open and honest communications;
2) Recognize humanity's tendency to categorize;
3) Demonstrate that stereotypes, regardless of how they affect attitudes, are a part of everyone's memory bank;
4) Raise stereotypes into the citizen advocates' consciousness so the advocates may monitor their own assumptions and expectations and deal effectively with stereotyping in others who relate to their proteges;
5) Develop an understanding that all human beings are unique.

REFERENCE: Attitudes, ed. Marie Jahoda and Neil Warren, 1966, Penguin Books.

Stereotype Exercise and Discussion

1) Briefly discuss the purpose of the exercise and define what you mean by "stereotype". A general definition of "stereotype" might be a fixed or conventional concept of people based on a preconceived and unreasonable judgment or opinion. Such a judgment is usually an unfavorable one marked by suspicion, fear, intolerance

or hatred. Carefully explain that you wish to elicit stereotypes that many people harbor or that the volunteers have heard from teachers, co-workers, relatives, the media, etc. In effect, assure them that what they say will not be interpreted as their personal beliefs or feelings. Stress this or you will elicit total silence!

2) Write on the chalkboard "People Who Are Polish", or Black, Jewish, Chinese, German, Mexican, etc.

3) Elicit stereotypes from the volunteers relating to the group of people being discussed. Usually, the coordinator must initiate the activity and should choose a stereotype that is very familiar, such as "people who are Black have an innate sense of rhythm". Write down everyone's contribution regardless of how appropriate the group feels it is. Repeat this exercise using another group of people. A great favorite is "People Who Are Women" as it leads to very animated participation.

4) Write on the chalkboard "People Who Are Mentally Retarded".

5) Elicit stereotypes from the volunteers relating to mentally retarded people. You may have to nudge and hint a bit as your volunteers may be reluctant to say anything negative about this group. Also, people tend

to have fewer stereotypes of mentally retarded persons because the subject of mental retardation was not openly discussed for so many years.

6) Discuss the reasons for stereotyping. Elicit as much of this discussion from the voluntears as possible. Points that should be touched upon include the need to quickly evaluate unfamiliar situations and the desirability of simplifying complex social situations. Point out that these needs are not in themselves bad.

7) Discuss the process of stereotyping. The procedure might include first receiving second-hand information, generalizing this to all people within a given group, then reinforcing the stereotype with a single first-hand experience.

8) Discuss the negative aspects of stereotyping. These may include: being based on false assumptions; being too simple and too general; the possibility of using negative stereotypes to maintain an unjust status quo. For instance, because many women perform generalized tasks as housewives, it might be argued that evidence indicates they are unable to perform highly specialized tasks such as men perform who are physicians, lawyers, insurance salesmen, etc.

9) Discuss the uniqueness of human personalities and the highly individualized quality of interpersonal relationships. The citizen advocates should be drawn to

the conclusion that although their proteges are mentally retarded, they still have unique potentials and individual strengths and weaknesses.

SECTION II

GUIDELINES FOR CONDUCTING THE TRAINING PROGRAM

PART II: A BASIC ORIENTATION TO MENTAL RETARDATION

Steps For The Instructor:

step one - state the purposes of the activity by referring to the objectives for PART II: A BASIC ORIENTATION TO MENTAL RETARDATION.

step two - conduct the activity according to the outline provided under "AN OVERVIEW OF THE NATURE AND CAUSES OF MENTAL RETARDATION", pp. 19-21.

step three - answer questions relative to the material covered in "AN OVERVIEW OF THE NATURE AND CAUSES OF MENTAL RETARDATION".

OBJECTIVES FOR PART II: A BASIC ORIENTATION TO MENTAL RETARDATION

The purposes of this activity are to:

1) Give the citizen advocate background on the nature, causes and prevalence of mental retardation.
2) Help the citizen advocate distinguish between mental retardation, disease processes, and "mental illness".

REFERENCES

Book III, Avenues To Change: Effective Advocacy, NARC, 1974.

Book I, Residential Programming for Mentally Retarded Persons: Prevailing Attitudes and Practices in the Field of Mental Retardation, NARC, 1972.

Prevention Handbook: To Our Children's Children, NARC, 1975.

AN OVERVIEW OF THE NATURE AND CAUSES OF MENTAL RETARDATION

AAMD Definition: (See Book III, p.7):

Define mental retardation as expressed in AAMD's definition:

> "Mental retardation refers to significant sub-average general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period."

Explain the underlined terms. Explain that mental retardation is not an illness but is a condition.

Prevalence: (See Book III, pp. 7-10)

Inform the new advocates that an estimated six to seven million Americans are at some point in their lives classified as mentally retarded.

Introduce the terms mildly, moderately, severely and profoundly retarded, explaining the relativity of these terms and the type of data upon which such classifications are based.

Reiterate the negative impact of inappropriate labels (stereotypes) and advise the citizen advocates of their widespread usage, i.e., "our TMR's" rather than "the students in Miss Nelson's class".

Causes: (See Book III, pp. 10-11)

Discuss the major causes of mental retardation. Your comments might include the following:

- During pregnancy: (e.g., toxicity, malnutrition, German measles, glandular disorders, and genetic defects)
- At birth: (e.g., physical accident and anoxia)
- After birth: (e.g., physical accident, fever, malnutrition, and lead poisoning)

Explain that, according to the President's Committee on Mental Retardation, 75% of all mental retardation is thought to be related to conditions of poverty. Discuss this relationship (lack of adequate pre- and post-natal care, malnutrition, lead poisoning, etc.).

In addition to the physical influences of poverty, discuss the social implications, the lack of opportunity to experience developmental tasks that build competencies and skills towards expectations of the dominant culture.

Again, stress that although a disease process may in some cases have caused mental retardation, that mental retardation itself is a condition and not an illness.

Distinguish also between mental retardation and mental illness (see Book I, Residential Programming For Mentally Retarded Persons, p.6).

PART III: HISTORY OF ATTITUDES AND PRACTICES CONCERNING MENTALLY RETARDED PERSONS

Steps For The Instructor:

step one - discuss the purposes of the activity by referring to the objectives for PART III: HISTORY OF ATTITUDES AND PRACTICES CONCERNING MENTALLY RETARDED PERSONS.

step two - show the slide presentation, "History of Mental Retardation" which consists of slides #1-#54 in the 35mm carousel and the script for the narration. Slide #1 should appear on the screen where the number one is indicated in the script, and slide #2 should appear where the number two is indicated and so on. The instructor should read the script.

In the event it is not possible to show the slide presentation, the instructor should use the lecture outline, "Historical Overview of Mental Retardation". (See Appendix A, pp. 103-105)

step three - discuss the philosophical basis for programs and services and the changing trends, using the presentation outlines on pages 44-45.

step four - answer questions relative to the slide presentation or the lecture.

OBJECTIVES FOR PART III: HISTORY OF ATTITUDES AND PRACTICES CONCERNING MENTALLY RETARDED PERSONS

The purposes of this activity are to:

1) Provide the citizen advocate background on the history of mental retardation;
2) Give the citizen advocate an awareness of the negative attitudes of society towards the handicapped, the traditions from which these attitudes evolved, and the myths about mental retardation that they perpetuate; and
3) Help the citizen advocate develop an evaluative framework for determining the appropriateness of philosophies which underlie programs and services for mentally retarded people.

REFERENCES

Wolf Wolfensberger, "The Origin and Nature of Our Institutional Models", Changing Patterns in Residential Services for the Mentally Retarded, ed. R. Kugel & W. Wolfensberger, PCMR, 1969, pp. 59-171.

Book III, Avenues To Change: Effective Advocacy, NARC, 1974.

SLIDES

HISTORY OF MENTAL RETARDATION

1

Mental retardation has always been a problem of mankind, for mentally retarded people have always been with us. Among primitive peoples, however, the practice of infanticide, or infant-killing, was the rule, and all children who exhibited abnormal characteristics, either physical or mental, were killed. In their general hand-to-mouth existence, there were no surplus resources to support those who could not fend for themselves. Therefore, these aboriginal societies appear to have a low prevalence of mental retardation. It was not until the eighteenth century that anyone made any distinction between emotionally disturbed and retarded people, a problem we still face, in part, today. Therefore, most historical references to the so-called

1 - History of mental retardation

2 - Ethiopian herdsman

3 - People beside hut

"mad" can be assumed to include mentally retarded persons.

[4] The Greek city-states, like all other societies of the time, practiced infanticide during their early development, but oddly enough they kept the practice well into their highly-cultured era. "Exposure", [5] as their ritual was called, took the form of a Committee of Elders inspecting every neighborhood newborn for weakness or obvious defect. An infant found to be imperfect was assumed to be an accident, which should be returned to the inattentive dieties. The infant was simply taken to the local mountaintop and left to die.

[6] Later, Athens and the other more sophisticated and relatively wealthy cities like Thebes and Corinth developed considerable curiosity and

4 - Bronze head

5 - Exposure

6 - Acropolis

began to keep any unusually developed persons to observe and to search for reasonable explanations of their abnormalities. Lacking scientific experience to find factual explanations for natural phenomena, the Greeks often invented fanciful theories. For example,[7] the Ancients had always been interested in epilepsy, which they called the "falling sickness". The later Greeks came to feel that people in seizure were, in fact, speaking to the gods, and they treated them accordingly. And so we see a complete reversal of attitude toward the exceptional individual during the life span of a society: a cycle from complete unacceptance to pampered luxury.

[8] The Romans were more than casually interested in human abnormalities. Nero's tutor, Seneca,

7 - Temple interior

8 - Slave

and several other intellectuals left notebooks about those whom they described as "feeble-minded". Those documents record the results of various training experiments.

9 The numerous Teutonic (or Germanic) invasions during the first centuries of the Christian Era left Western Europe in ruins, ushering in the "Dark Ages". Life again became a hand-to-mouth existence with no place for the totally dependent.

9 - Temple ruins

10 Christianity became the dominant religion, but utterly LOST in the rise of the darker superstitions and in the belief that anything unusual represented a demon was St. Paul's admonition to "comfort the feeble-minded". Only occasionally during this period do we find a monastery or convent sheltering a child with Downs syndrome or cretinism, thinking the child to be an angel

10 - Priest/demons

because of unusual appearance and a gentle disposition.

11 "The Age of Faith" is what the Middle Ages were called, but the "Age of Fatalism" might better describe the era. Anyone meddling with things as they were was suspected of tampering with the will of God. 12 In this artist's concept of medicine, taken from a book of prayers, we are shown the painter's contempt by the inverted funnel symbolizing quackery; the Church watches carefully, and a comical statement is made on the folly of educating women.

13 Attempts at experimentation were strongly mixed with magic and sorcery. Science, as shown in this picture of a typical laboratory, was the domain of the alchemist, who seemed to understand and respond to the needs of the disabled.

11 - Nun

12- Doctor and Patient

13 - Laboratory

14
Only the Eastern part of the Old Roman Empire and the New Arabic Kingdoms kept the old knowledge from disappearing completely.

14 - Mosque Interior

15
Although there are no written records of attempts to train or treat retarded people during the Middle Ages, this does not mean that there were none living at this time. This woman's face was painted by Pieter Bruegel. She is obviously microcephalic, but apparently the requirements of being a peasant hausfrau were not beyond her capabilities. As long as her behavior protected her status as a "face in the crowd", so to speak, she was unmolested by the authorities.

15 - Shepherds

16 - Woman's head

17 - Town Square

18
The practice of keeping a "fool" as an entertainer in wealthier households provided another loophole for survival for a few of the handicapped.

18 - Fool making toast

19

The traditional jester's costume you see here is now believed to have been developed to take advantage of the involuntary movements of persons with athetoid cerebral palsy, for the bells sewn on the extremities rang continuously. If this sounds cruel, remember that the alternative was an untimely death.

19 - Jester

20

As things began to stabilize, and a sense of security developed, some handicapped persons were allowed to "exist" like these beggars at a city gate.

20 - Beggars

21

As the Rennaisance brought with it the beginning of the countries we now know in Europe, powerful kings emerged and continued the old practice of keeping clowns. Some kings actually had quite unusual collections of all manner of human oddities and "freaks". 22 This young woman

21 - Castle

22 - Woman Full Length

was one of several people with the rare Cornelia DeLange syndrome who was kept as a curiosity by da Vinci's last patron, Francis I of France. It is easy to imagine how persons afflicted with this unusual syndrome may have been the basis of the werewolf folk tales we all know today.

By the fifteenth century, Europe was divided.[23] The Northern countries were engrossed in developing Protestantism, which, in its first stages, relished severely harsh doctrines which left no room for unusual behavior. This age of ferment brought with it the Reformation, stimulated by the new religious zeal.[24] The early reformers -- Luther and Calvin in particular -- were filled with harsh interpretations of nature, which they believed demanded total conformity. Luther himself described people who were epileptic as

23 - Church

24 - Luther

25
"filled with Satan", and, when shown mentally retarded children, always recommended drowning as a righteous treatment for these so-called "soulless creatures". In England, the term seizure first meant "seized by the devil". Southern Europe seemed more easy-going for the time being, particularly in the upper classes.

25 - Devil in a sheet

26
The Royal Court of Spain, as we see here, had not yet worked itself into a fever over conformity, for this painting by the court painter Ribera shows a clown kept by the King of Spain for the amusement of the court.

26 - Boy with flower

27
This painting, also by Ribera, shows another boy with multiple handicaps who was protected by the Crown and lived better than the average Spaniard of his day. He seems to have a spinal deformity, a club-foot, a deformed hand and

27 - Boy with pole

possibly Hutchins teeth, indicative of congenital syphilis.

28
Philip IV of Spain was fortunate enough to have had the magnificient Velasquez as his court painter. Velasquez painted in a vast palace which approached becoming an asylum for mentally retarded people, for from all over the country they were sent to the King's protection. 29 The king's most valued clown was this little cretin gentleman who, Velasquez noted, was paid about the same as the court painter. At one time he was exiled because of the grossness of his jokes, but was so missed that he was shortly recalled to court.

30
Here is a dwarf painted by Velasquez. Nothing is known of his mentality but, as mental retardation is more common among dwarfs than

28 - Man seated by Rock

29 - Man's Head

30 - Dwarf

among people of average growth, we may guess he may have been retarded. We may assume so because, knowing the customs of the day and now looking at this picture, we see another gentleman who definitely wanted people to know he was not retarded. He had himself painted with a conspicuous book and a set of writing equipment, showing he was an educated gentleman.

31 - Man with book

By this time our own country was beginning to develop. From the first, the North and South were quite different as far as motives and goals were concerned. Those Europeans who settled in the Southern areas generally brought with them a Roman Catholic or a High Church of England tradition of religion, which meant a calm or even disinterested attitude toward handicaps. There was no moral significance placed on

32 - Boats landing

33 - Plantation

retarded people, but if a profit could be made by[34] bonding a person who was mentally retarded to a farmer, it was quickly done.

34 - "Auction"

In the Northeast, however, we saw another[35] religious revival under way called Puritanism. Here, nonconformity was again considered diabolical. When the infamous witch trials occurred, mentally retarded people figured in them,[36] for their unusual behavior made them highly noticeable in the community. They were frequently either considered witches or evidence of the witches' destructive action. The image persists today of the old crone living ill-kempt and alone, except for possibly a few cats, feared by her neighbors as having strange powers.

35 - Loghouse

36 - Witch trials

Moving back to Spain in the late eighteenth[37] century, we find that the counter-Reformation

37 - Pope

has brought a change in the emotional climate. Revival of strict rules for living and conformity brought the conditions illustrated here: 38 a Goya painting of a hospital in Madrid, where mentally retarded and emotionally disturbed people were again thrown together.

38 - The Madhouse

Another sketch from this hospital shows a 39 patient who may have been retarded or insane. Possibly, he became both with this treatment.

39 - Sketch of bound man

In England we see a little improvement. This 40 is Bethlehem hospital, popularly known as "Bedlam" from which our word for utter confusion and noise derives. Much of the hospital's revenue came from charging admission for tours, which became popular among the eighteenth century gentry. It was fashionable to watch the antics of the "mad" folk. Cruel as this might seem,

40 - Bedlam

some good did come of it. Through this exposure, the public began to see what had previously been kept secret and this brought on a period of reform.

41 - Grapes

41 Concurrent with the development of scientific investigation, France became the center of experimental treatment to aid a wide variety of handicapped persons. A physician named Itard found near his home at Avignon a "ferral", or wild boy.

42 - Wild boy

42 Capturing and naming the boy Victor, Itard hit on the theory that the child was mentally retarded, possibly because of his having had no opportunity to learn social behavior. Determined to "cure" him, Itard kept Victor for five years. After this time the good doctor decided he had failed entirely because Victor had not learned perfect French.

43 Itard's papers about his experiment did stimulate an admirer of his named Seguin to begin a movement for the establishment of schools to cure what was then called "idiocy". But shortly thereafter Europe had its enthusiasm for such schools blunted by a scandal-tarnished collapse of such a so-called "colony" in Switzerland.

43 - Document

44 So Seguin emigrated to America, where he found a population quite ready to accept his ideas of institutions for the mentally retarded. Throughout the nineteenth century, residences for mentally retarded people sprang up across the country, but most of them followed similar unfortunate plans of evolution.

44 - Steel workers

Someone, usually a physician, got enough community support to buy a farm 45 where the

45 - Small institution

mentally retarded people from the neighborhood could have a setting for useful occupational training and partial self-support.

As word of the residences spread, mentally retarded people who had been hidden away or barely tolerated by the citizenry were very quickly "put away". Unfortunately, the new interest only stimulated an unready public into the general construction of custodial institutions as a conscience salve. The idea was to no longer abuse these unfortunates, but to keep them out of sight.

Then the farm became a small factory or[46] cottage industry in order to provide activity for the residents. Soon congestion made meaningful activities for everyone almost impossible, and hospital-type units for the multiply-handi-

46 - Institution with smoke-stack

capped appeared. The casual visitor must have felt some tinge of guilt at seeing those who were less retarded having to care for those who were more severely handicapped. Then, to add to these woes, legislation or policy declared that these "poor souls" should not be required to work. As education and training programs were not provided in place of work, the residents were retired to benches for their waking hours.[47]

47 - Bench

So now we had strange, idle people who needed supervision to keep them on those benches!

Walls and fences went up to reassure the community that these "strange" people would not be able to seek adventure outside.[48] An emerging nation intent on growth and production utilized its able-bodied citizens but had no place for the mentally retarded. Medical services and[49]

48 - Large institution

49 - Classroom

public education were scanty for the general population and totally unavailable to the handicapped. As a result the institutions continued to grow.

Others arrived at the institution with severe emotional problems, so isolation facilities[50] were needed to prevent destructive behavior. The appearance of these facilities clearly lets the uninformed know that punishment went with safety.

Several spurious studies at the turn of the century seemed to prove the growing belief that mental retardation was the result of heredity, sin, or even excessive drink. So all thought of training disappeared and custodial care became the goal.

"Warehousing"[51] is the name given to what was going on inside the buildings which had

50 - Locked door

51 - Ward

such well-kept exteriors.

52
Dehumanizing bath and sanitary facilities made it possible for a very few employees to move great numbers of residents through them.

52 - Showers

53
There was little effort to teach socialization. And if you stop to think for a moment, you will realize that facilities like these do very little to give the resident the opportunity to learn to use an ordinary bathroom.

53 - Toilets

54
And for the few who didn't want to sit on those benches for sixteen hours every day, man became very inventive! Years later, drugs were often used for the same effect.

54 - Drawing of restraints

55
Here we see the desired effect of custodial care: this "perfect" child! She has learned her lesson well....

55 - Girl on bench

Not until the late 1950's did someone

finally realize that this child had learned how to perform a very difficult task: it is extremely hard to sit quietly for a long period of time. And with this realization came the feeling that the ability to learn this task might indicate the ability to develop.

56

56-Credit slide

END SLIDES

(This slide presentation was adapted from "History of Mental Retardation" by the Employee Training Department, Austin State School, Austin, Texas, 1969.)

(This activity continued on page 44.....)

Common Models (See Book III, page 14)

Explain that a human management model is the typical expression of a concept or pattern. A service model for mentally retarded persons consists of a set of premises or predictions which may dictate the location, design and operation of the service facility. The total environmental setting reflects these predictions.

In the United States, service models have typically been based upon the following six characterizations of mentally retarded people:

1) a sub-human organism
2) a holy innocent
3) a burden of charity
4) a menace
5) an object of pity
6) a sick person

Discuss the consequences of viewing mentally retarded people in these ways.

The Changing Thrust (See Book III, pp. 14-16)

1920's: When institutionalization of mentally retarded persons did not stop the incidence of mental retardation, professionals were forced to re-evaluate their assumptions about the hereditary nature of retardation.

1930's and 1940's: World-wide depression followed directly by World War II left social programs as a very low priority.

1950's: Peace, prosperity, decline in unemployment and the development of publically sponsored social programs gave Americans an opportunity to take a new look at mental retardation. The National Association for Retarded Citizens (Children), a progressive consumer advocacy group, was formed in 1950. The American Association on Mental Deficiency came out with its first standards for institutions in 1952.

1960's: The Kennedy administration brought mental retardation to the attention of the public, formulating the President's Panel on Mental Retardation in 1962. The Joseph P. Kennedy, Jr. Foundation supported research and the Special Olympics. The President's Committee on Mental Retardation began operation in May of 1966.

1970's: The Accreditation Council for Facilities for the Mentally Retarded published accrediation standards for residential facilities in 1971 and for community agencies in 1973. New community-based programs are being established in America, based on the normalization principle and designed according to the developmental model.

PART IV: THE NORMALIZATION PRINCIPLE

Steps For The Instructor:

step one - discuss the purposes of the activity by referring to the objectives for PART IV: THE NORMALIZATION PRINCIPLE.

step two - define the Normalization Principle and briefly discuss its origin and underlying rationale.

step three - show the slide presentation on "An Overview of the Normalization Principle". The Instructor should narrate the slide show by reading the script on pages 49-57. The number for the slides in the carousel correspond to the numbers indicated in the script. If it is not possible to use the slide presentation, the instructor should use the script as an outline for the lecture.

step four - distribute the Normalization Exercise Cards #1-#7 to each advocate participating in the training session. Read and discuss one card at a time in the sequence indicated. The instructor will note that points for discussion are indicated for each situation, if the advocates do not identify the major problem which is stated in the situation. (Instructions for the preparation of these cards are included in the text on page 58.)

step five - answer questions relating to the discussion and activities on Normalization.

OBJECTIVES FOR PART IV: THE NORMALIZATION PRINCIPLE

The purposes of this activity are to:

1) Explain the normalization principle as a viable alternative to traditional models of mental retardation;

2) Demonstrate how Citizen Advocacy supports the normalization principle; and

3) Help the advocate view his protege as a citizen.

REFERENCES

Bengt Nirje, "The Normalization Principle and Its Human Management Implications", Changing Patterns in Residential Services for the Mentally Retarded, ed. R. Kugel & W. Wolfensberger, PCMR, 1969, pp.

Book I, Avenues To Change: Citizen Advocacy for Mentally Retarded Children: An Introduction, NARC, 1974.

Book III, Avenues To Change: Effective Advocacy, NARC, 1974.

Wolf Wolfensberger, The Principle of Normalization in Human Services, National Institute on Mental Retardation, Toronto, 1972.

NORMALIZATION

Discuss the definition and explanation of normalization as outlined below. When you reach the point in the outline entitled "An Overview of the Normalization Principle", use the slide presentation and follow the script given under that section. If a slide projector is not available, make a presentation according to the same general outline.

Definition: (See Book I, pp. 21-22).

Define normalization according to Wolfensberger:

> Normalization is "utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible".

Explanation:

Indicate how the impetus for the normalization principle in America derived from the Scandanavian attitudes and programs.

Discuss how the protege should have every opportunity to lead as normal a life as is possible for him within the limits of his capabilities.

AN OVERVIEW OF THE NORMALIZATION PRINCIPLE

1 - Normalization

1 Normalization is the name given to a principle underlying a current trend in services for mentally retarded citizens. In order to understand the normalization principle, it is important to consider what "normal" means.

2 - Rhythm of the day

2 What is normal is determined by the activities of the majority of people who live in a given society. For example, in this culture, it is normal on a daily basis to awaken to the ringing of an alarm clock, shower, and share breakfast with one's family or roommates before going off to work.

3 - Rhythm of the week

3 During a normal week, the average citizen resides in one location, works in another part of town, and spends weekends and other leisure hours at recreational facilities--the movies, the bowling alley - away from home.

4 During the passage of the year, the average person wears clothing appropriate to the weather, donning coats and scarves during the winter and enjoying summer sunshine in light weight clothing and sandals. Finding joy in the changing of the seasons and celebrating their respective holidays are also part of normal lifestyles.

4 - Rhythm of the year

5 When very young, children stay close to home and the supervision of their parents. Later, young adults go off to school with peers, then out into lives and homes of their own. When people reach advanced age, retirement and possibly a more sheltered living arrangement are part of the normal passage and stages of life.

5 - Rhythm of life

6 All of us, including those who are mentally retarded, have a right to live in the community in homes and apartments which are similar to others in a neighborhood. We want to and should

6 - Residential settings

have access to churches, schools, health services, and shopping areas.

7 - Economic standards

7 People in our culture have a right to be justly compensated for the work they do, and to spend their money as they see fit. Even people who need assistance in budgeting should have a voice in how their money is used, and they should have pocket money for small expenditures.

8 - Making choices

8 Although it is necessary for other people to make decisions for the best interests of children, it should also be remembered that both adults and children should at least assist in making choices in regard to their residence or vacation, and with whom they wish to associate.

9 - Privacy

9 All people are entitled to privacy. A person should have access to a room or area which permits spending time undisturbed. The privacy of our personal lives is important to us as human

beings.

10 Sharing belongings is great sometimes, but the pride of ownership is important too. Remember your very own first car? Or the special ring that a good friend gave you for your birthday. Personal possessions, and closets and drawers to put them in, reflect to us a sense of who we are as individuals.

10 - Personal possessions

11 Dating, dancing, and making friends with members of the opposite sex are very important for developing people. Regardless of whether one chooses to live alone or with others, relating in a mature way to both sexes is essential to a realistic orientation to life.

11 - Human sexuality

12 Anyone who lives in a room like this will probably not be viewed as a unique individual with the rights we have just reviewed.

12 - W.rd

13 On the other hand, the resident of this room

13 - Bedroom

is more likely to be seen, and see himself, as a person with individual tastes and preferences who has a right to a normal lifestyle.

14 A person who lives behind a fence is a person who is likely to be viewed as being dangerous to himself and others. 15 In contrast, a person who lives in this house is probably seen as a neighbor, possibly a friend, who is not much different from the rest of us.

16 The normalization principle means different things in different cultures. Normal patterns vary from one country to another. 17 Cultural norms vary from one type of civilization to another. Determining what is normal in your community is best accomplished by viewing another's situation from your own perspective, by "putting yourself in the other person's shoes". For example, how would <u>you</u> like being sterilized against your will

14 - Locked gate

15 - House

16 - Japanese dancer

17 - Arab girl

or even without your knowledge;[18] or having people talk about you to your companions and not to you; or living in an institution without alternative options for residence?

18 - "Family History"

[19] The normalization principle assumes that people fulfill the roles that others design for them. "Failures" will fail, "criminals" will commit crimes, and "normal people" will behave in socially acceptable ways. Positive expectations about a person's abilities help that person achieve his full potential and create a positive self-image.

19 - Mirror

[20] It is important that citizen advocates help their proteges behave in socially acceptable ways. Discrimination and ostracization result from the ability to identify people as belonging to a negative category. People who are labelled as deviant are shunned. Well-groomed, acceptably

20 - "Retardate"

behaving people blend into society and are tolerated.

21 Normalization applies to programs and services as well as to lifestyles. Attending public schools, integrated day training programs or work stations in industry, and living in small group homes or in the natural home are all normalizing activities. Although most of these programs offer special assistance in order to help mentally retarded people maximize their potential, they are based in the community. Mentally retarded people are thus exposed to non-retarded persons and typical lifestyles so that these handicapped people may learn to adjust to and use the community.

22

Citizen advocates can create normalizing experiences for their proteges almost every time they get together. 23 For example, learning about

21 - Boy at blackboard

22 - Family at dinner

23 - Girl with toothbrush

hygiene and taking care of one's physical appearance is an important part of normal life.

24 Learning to use public transportation opens the way to vital services and fun-filled adventures.

24 - Bus

25 Learning to utilize means of communication generates increased social skills and provides access to important information.

25 - Boy on phone

26 Getting together with friends and enjoying good times is part of Citizen Advocacy.

26 - Party

27 Eating out is a wonderful way to share and to celebrate, and also offers the opportunity to learn a variety of social skills.

27 - Restaurant

28 Joint endeavors in the kitchen provide an opportunity to learn about nutrition, meal planning and preparation. While sharing these and other normalizing experiences, advocates can serve as models of dress and behavior, give

28 - Woman in kitchen

tactful guidance, and encourage their proteges to make choices and then support them in their decisions.

29
The advocate is an expert in the field of everyday, normal living. Many of the day-to-day skills the advocate takes for granted may represent new information for the protege to assimilate, and new skills to be acquired.

29 - Citizen Advocacy logo

END SLIDES

("Normalization Exercise" continued on page 58)

Normalization Exercise

INSTRUCTIONS FOR PREPARATION OF CARDS FOR THE "NORMALIZATION EXERCISE":

Prior to the training session, type up 3"X5" index cards bearing the information related under the Situation sections in the following exercise. Prepare them so that they contain only one situation per card and are numbered according to the sequence given below. For example, Card #2 would read:

"CARD #2

You want to read Jane a story, but she wants to turn the pages of the book. What should you do?"

The Discussion sections of the exercise should not be included on the card. Make a sufficient number of sets of cards (perhaps ten) so that each advocate may use one complete series of cards #1-#7. These cards should be returned to the instructor at the end of the exercise and used again in future training sessions.

In view of what has been said regarding normalization, have the advocates discuss the following situations. It is very important that the instructor remind the volunteers of the relativity of each situation during the discussion periods. Each person is unique and may require different approaches in handling each situation. Mentally retarded persons functioning at different levels might respond in different ways and have different needs.

In each of the following situations, what are the volunteers' reactions to, and what should they as advocates do, if:

Card #1

Situation: "Six men have moved from the institution into a training hostel. It is located in a middle-class residential neighborhood. You can recognize it by the sign over the door that says 'Halfway House for Retarded Men'. What is your response?"

Discussion: The advocates should readily identify the inappropriateness of a sign which designates this house as being special, or different in any way from the other homes in the neighborhood.

Card #2

Situation: "You want to read Jane a story, but she wants to turn the pages of the book. What should you do?"

Discussion: The advocates might propose some solutions that take Jane's desires into account: let her do as she pleases, invite her to tell you a story that goes with the pictures; let her turn the pages first and then read her the story. The advocates may wish to modify Jane's behavior by introducing contingency techniques, i.e., "if we read the story, then you can..." or "If we don't read the story, then you will have to..." making sure to follow through on a consistent basis.

Card #3

Situation: "Terri is sixteen and her mother is willing that she have a girl friend. However, the mother is against Terri having any contact with boys. As Terri's advocate, how do you respond?"

Discussion: The advocates should recognize Terri's social needs, but should also recognize the long-term nature of finding a solution to this kind of situation. Have the advocates propose some long-term means of overcoming the mother's hesitancy: gaining the trust of the family, then possibly introducing a male friend to accompany the advocate and protege on outings, accompanying Terri to social events where males are present, and later inviting mother to attend as well. The advocate should also be prepared to help Terri deal realistically and appropriately with men. This may include the advocate's providing thorough and on-going sex education.

Card #4

Situation: "Bill is eighteen years old and lives at a men's group home. The house supervisor has to punish him every evening by assigning him extra work because he eats too slowly or doesn't clean up his plate. How do you, as advocate, react?"

Discussion: The advocates may have a wide variety of suggestions for this, but, again, they should recognize Bill's right to eat in his own way and at his own pace. The advocate could encourage Bill to lodge a complaint with the supervisor; this could be followed up by the advocate speaking to the supervisor, or, if necessary, the supervisor's superior. Or, the advocate could join the residents for dinner and eat just as slowly as Bill and see what happens. The advocate should also help Bill to realize his responsibilities: if he is holding up someone else's work in the kitchen, he should accept the responsibility of cleaning his own dishes, etc.

Card #5

Situation: "John wants to marry Rita but their counselors feel that they are not ready to handle the responsibilities of marriage. Rings, dress and wedding cake have been purchased. The wedding is canceled. As advocate, what is your opinion?"

Discussion: The advocate should realize that a great deal more information is required before he can form an opinion. For instance, he should discuss the matter at length with the counselors. Under any circumstances, the couple has a right to know exactly what their legal rights are in the matter. Hypothetically, if the advocate should feel that the counselors

are being overly protective and that the couple is ready to marry, he should encourage them and assist them in making the necessary adjustments and help the counselors learn to "let go". If they are really not ready, the advocate should help them prepare for these responsibilities. If no real potential for marriage exists, the advocate should help the protege to learn to accept the reality of the situation and to learn to enjoy a healthy, satisfying single life.

Card #6

Situation: "Twenty-year-old Jim wants you to like him. He walks up and hits you in the stomach. How do you react?"

Discussion: A possible response might be to hit him in the stomach and see how he likes it. A more constructive method might be to simply tell him you don't want to be hit, and that you cannot be his friend if he persists in using violence. After several reminders and coincident offers to shake hands in greeting, the advocate might refuse to interact with him until Jim agrees to use more conventional greeting methods.

Card #7

Situation: "Mary had been in an institution a long time. Now living in the community, she often asks

others to do things for her, saying 'I can't'. What should you do?"

Discussion: The advocates may not realize the ways in which institutional living fosters dependence, and this should be illuminated. In dealing with such a problem, the advocate should ask Mary's permission to show how it is done, demonstrate the task, and then refuse to do anything for Mary that the advocate feels she is capable of doing; the advocate should do everything possible to help her learn the skills she needs to accomplish specific tasks.

PART V: THE DEVELOPMENTAL MODEL

Steps For The Instructor:

step one - discuss the purposes of the activity by referring to the objectives for PART V: THE DEVELOPMENTAL MODEL.

step two - discuss the Developmental Model by using the outline which appears on pp. 65-66 and indicated sections of *Avenues To Change*, Book III.

step three - answer questions relative to the discussion on the Developmental Model.

OBJECTIVES FOR PART V: THE DEVELOPMENTAL MODEL

The purposes of this activity are to:

1) Explain the Developmental Model as a viable alternative to common models; and
2) Demonstrate the basic compatability of the Normalization Principle and the Developmental Model.

REFERENCE

Book III, Avenues To Change: Effective Advocacy, NARC, 1974.

UNDERLYING ASSUMPTIONS AND GOALS OF THE DEVELOPMENTAL MODEL

Developing Beings (See Book III, pp. 21-22)

Explain how we are all changing and growing beings; that everyone can learn, grow and develop, each at his own pace.

The Developmental Model assumes that:

1) life is change;
2) development is sequential; and
3) development is modifiable.

Programs and services which are based on the developmental model have the following goals:

1) increasing the mentally retarded person's control over his environment;
2) increasing the complexity of the mentally retarded person's behavior; and

3) maximizing the human qualities of the mentally retarded person.

The Relationship of the Developmental Model to the Normalization Principle

Explain that the Normalization Principle and the Developmental Model are generally compatible approaches for providing programs and services for mentally retarded persons. The Normalization Principle would be fruitless, for example, if its adherents did not accept the premise that all people learn, develop, and grow on an on-going basis.

In discussing differences between the approaches, it should be pointed out that the Normalization Principle is a technique for maximizing development while the Developmental Model is a framework in which various techniques may be used for maximizing development. For example, programs and services which are based on the Developmental Model may utilize a normalized environmental setting if that type of setting is most conducive to maximizing development. However, needs of the individual should determine the specific approach or techniques to be used, thus a normalized approach should be used unless a specialized environment (e.g., an automated or mechanized setting) is necessary for maximizing development.

PART VI: A FINAL WORD ON RISK AND COURAGE

Steps For The Instructor:

step one - discuss the purposes of the activity by referring to the objectives for PART VI: A FINAL WORD ON RISK AND COURAGE.

step two - conduct the activity by following instructions under Risk and Courage, p. 68. Read the passage by Perske to the advocates.

step three - answer any questions the advocate may have regarding any material covered during the entire First Training Session.

OBJECTIVES FOR PART VI: A FINAL WORD ON RISK AND COURAGE

The purposes of this activity are to:

1) Illustrate the dignity of risk in people's lives; and
2) Demonstrate the courage and adaptability of some mentally retarded citizens.

REFERENCE

The Dignity of Risk, Bob Perske, NARC,

RISK AND COURAGE

Briefly discuss the element of risk as an aid to growth and development and as a part of normal life. As an example of the courage of some mentally retarded people in the face of extreme danger, read the following passage to the advocates. Quoted with permission from New Directions For Parents of Persons Who Are Retarded by Robert Perske. Copyright © 1973 by Abingdon Press.

> "In a book recently published in German, Wilhelm Teufel describes some courageous human responses of retarded children and adults in the 700-place institution at Stetten, Germany, when Adolph Hitler began his euthanasia program. In 1940, two gray buses with windows painted gray arrived periodically. They were

loaded with residents who were "transferred" to a castle some miles away where they were gassed and cremated.

"Teufel points out that it didn't take long for some of these retarded persons to sense what was taking place. Then he described some amazing happenings. Some of the ambulatory persons became deeply concerned for the non-ambulatory, knowing they had little chance to fend for themselves. Many used their best wits to scout and plan special hiding places to which they fled every time they saw the Nazi buses coming up the road. One boy instinctively ran to his hiding place when the critical time came. He then returned after the buses were gone, saying, 'They didn't catch me. I'm smarter than they'. Karl fought with the driver and ran away shouting, 'I'll hang myself before I'll die like that'. Richard, who suffered from some spasticity, knew he did not have a chance. With calm and purpose he gave his pocket money and watch to his closest friend. He discussed the situation with his housefather. They even prayed together as he made himself ready to die like a man with dignity. 'Cool' Emily calmly got into line on the day her name was called and walked to the bus.

But as she came near the door of the bus, she calmly walked right on by and nobody even noticed. Later, when the bus was gone, she returned to the institution and busied herself with her assigned task of scrubbing steps. All this points up how persons who are retarded can, will, and should respond to risk with full human dignity and courage."

SECOND TRAINING SESSION

Time: Approximately 2-1/2 - 3 hours.

Attendance: This group will be comprised of new advocates who have attended the First Training Session. This meeting should take place within a week of the first session. The written invitations mailed prior to the First Training Session should have also indicated the date and time of this second session, but the coordinator should call the participants a day before this meeting as a reminder.

Materials: Basic equipment and materials for the training session include:

1) Chart of local community resources for mentally retarded persons
2) A pointer
3) One 35mm. carousel slide projector (optional, see page 79)
4) One movie screen (optional, see page 79)
5) Typed cards for "Examples of Advocacy in Action" (see page 83)
6) Typed cards for "Exercise in Wending Your Way Through the Bureaucratic Maze" (see page 88)
7) Orientation kits (see Part IV, pages 91-92)
8) Tables and chairs for the volunteers being trained
9) Pads and pencils
10) Refreshments
11) Ashtrays

TIMETABLE FOR SECOND TRAINING SESSION

This schedule indicates the maximum amounts of time which may be devoted to each activity in the second training session. Reference materials for the instructor are also listed.

Time	Activity	Reference Materials
30 min.	Part I: The Role of the ARC Lecture: "Citizen Advocacy and the ARC"	Into the Light of Learning
1 hour & 30 min.	Part II: Citizen Advocates' Roles and Responsibilities	Avenues To Change, Book III
-1 hour & 15 min	Lecture: "Basic Guidelines For Effective Advocacy"	
-15 min.	Group Work: "Examples of Advocacy in Action"	
15 min.	BREAK	
30 min.	Part III: Community Resources	
-15 min.	Lecture: "An Overview of Local Programs and Services"	
-15 min.	Group Work: "Exercise in Wending Your Way Through the Bureaucratic Maze"	

Time	Activity	Reference Materials
15 min.	Part IV: Resource Materials for the Citizen Advocate Group Discussion: "Orientation Kit"	

TOTAL TIME: 3 hours

PART I: THE ROLE OF THE ARC

Steps For The Instructor:

step one - discuss the major purposes of the activity by referring to the objectives under Part I: The Role of the ARC, p. 74.

step two - conduct the activity by expanding upon the lecture outline, "Citizen Advocacy And The ARC", pp. 74-76, which provides basic information on the national component of NARC. It will be noted that there has not been a distinct separation of the purposes and roles of the local, state and national levels of NARC. It is recommended that a knowledgeable ARC volunteer or staff member assist when the specific history, interests, and roles of the local or state ARC are discussed.

step three - answer questions concerning the activity.

OBJECTIVES FOR PART I: THE ROLE OF THE ARC

The purposes of this activity are to:

1) Help the advocate recognize similarities and differences between the corporate advocacy of the ARC and Citizen Advocacy;
2) Give the advocate a perspective on the history of advocacy and why the ARC adopted Citizen Advocacy as a project; and
3) Explain to the advocate the functions of the ARC and how it can benefit both advocate and protege.

REFERENCE:

Into The Light of Learning, NARC, 1974.

CITIZEN ADVOCACY AND THE ARC

Purpose of the National Component:

- organized in 1950;
- current membership includes more than 300,000 members who are affiliated with approximately 1,700 state and local member units;
- NARC is a nationwide organization which is devoted to improving the welfare of all mentally retarded persons;
- NARC serves parents, individuals, organizations and communities in jointly solving the problems caused by mental retardation; and
- YOUTH-NARC formed in 1967:
  - includes in excess of 25,000 members;
  - is for persons between ages 13 and 25; and

- is involved in providing services, assisting in creating community awareness, and understanding and acquiring first-hand knowledge of career opportunities in the field.

Programmatic Priorities of the National Component:

The goals of the organization between 1975-1980 are to:

- Achieve an increasingly adequate, consistent coordinated pattern and level of funding of all services needed by retarded persons and their families.
- Reduce the incidence of mental retardation resulting from specific, identifiable conditions such as malnutrition, infections, environmental toxins, genetic conditions, and environmental deprivation.
- Achieve an array of developmental institutional and community-based residential services for all mentally retarded persons, ensuring possibility of choice among a series of desirable alternatives.
- Increase the quantity and quality of research impacting upon prevention and amelioration.
- Ensure the legal rights of all mentally retarded persons in every state, working with appropriate individuals, and public and private bodies.
- Establish effective advocacy systems throughout the country in cooperation with interested groups and individuals to serve all mentally retarded persons and to support, monitor and evaluate all services impacting on such persons.
- Achieve appropriate educational, pre-school, continuing and compensatory education services for mentally retarded persons of all ages.
- Foster and/or develop demonstration models of comprehensive community services for mentally retarded persons within any specified area, including sparsely populated rural areas.
- Significantly increase the number of mentally retarded persons employed and improve their level of employment, and expand vocational and pre-vocational training.

- Improve the understanding and acceptance of, and commitment to, the cause of mental retardation by the general public and by specific target groups (e.g., physicians, judges, attorneys, legislators, and public school administrators).

Advocacy Methods for All Levels of the Association:

- public education;
- legislation;
- litigation; and
- direct monitoring of services and programs for mentally retarded persons.

Citizen Advocacy as a Microcosm of the ARC

The citizen advocate has many of the same purposes and areas of interest as the ARC. The significant difference between Citizen Advocacy and the ARC is that the advocate operates on a one-to-one basis and the ARC is a corporate advocacy system. Citizen Advocacy is a part of the overall ARC activities.

PART II: CITIZEN ADVOCATES' ROLES AND RESPONSIBILITIES

Steps For The Instructor:

step one - discuss the purposes of the activity by referring to the objectives under this section, PART II: CITIZEN ADVOCATES' ROLES AND RESPONSIBILITIES.

step two - conduct the activity by following the outline provided under this section.

step three - distribute the "Examples of Advocacy in Action" cards #1 and #2 to each advocate participating in the training session. Read and discuss each card in the sequence indicated. After the advocates have discussed the possible steps for solving the problem, relate to them what the actual solution to the problem was. (Instructions for the preparation of these cards are included in the text on page 83.)

OBJECTIVES FOR PART II: CITIZEN ADVOCATES' ROLES AND RESPONSIBILITIES

The purposes of this activity are to:

1) Define citizen advocates' responsibilities and obligations to the program;
2) Suggest activities in which advocates may wish to engage with their proteges; and
3) Cover the area of the proteges' rights and to suggest practical means by which advocates may help ensure these rights.

REFERENCE

Book III, Avenues To Change: Effective Advocacy, NARC, 1974.

BASIC GUIDELINES FOR EFFECTIVE ADVOCACY

Responsibility

Elaborate upon the concept that although citizen advocates have certain obligations to the Citizen Advocacy program, their primary responsibility is to their proteges.

Obligations to the Citizen Advocacy Office

Cite the following responsibilities as mandatory obligations:

1) The citizen advocate must submit monthly activity reports. This provides the coordinator with feedback on each relationship and provides the documentation essential to continued funding of the program.
2) Each advocate should be strongly encouraged to take advantage of monthly group meetings. This partici-

pation is necessary in order to answer questions as they arise, to benefit from the experiences of other citizen advocates, and to share his or her experiences for the benefit of others.

Legal Liability (see Book III, pp. 24-26).

Explain to the citizen advocates that they should:

1) Exercise reasonable caution while with their proteges;

2) Carry sensible insurance coverage; and

3) Keep their property and automobiles in good order.

Advocacy Roles (see Book III, pp. 22-25).

It may be desirable to show the NARC slide presentation "Citizen Advocacy: An Answer For Thursday's Child" at this time as a supplement to the following lecture-type presentation.

Explain the terms "expressive" and "instrumental". Explain that advocates should try to fulfill those needs they identify in their proteges and that, as time and circumstances change, so will the proteges' needs. At some times advocates may fill expressive roles; at other times, instrumental; and at times will simultaneously fulfill needs in both areas. Describe the various advocacy roles as outlined below:

- The Advocate-Companion: friendship, emotional reinforcement (expressive)
- The Advocate-Adviser: practical assistance and probably emotional reinforcement (instrumental or instrumental and expressive)

- Conservatorship and Trust: Administration of a dependent person's estate (instrumental)
- Toward the parent role: foster or adoptive parenthood (instrumental and expressive)

Duties of the Citizen Advocate

Convey the idea that no matter what role classification their relationships represent, citizen advocates are expected to:

1) Maintain an on-going, one-to-one relationship, and

2) Defend the rights and interests of their proteges.

Activities (see Book III, pp. 31-32).

Discuss how the coordinator will match citizen advocate and protege according to similar interests in order to obtain basic personality compatability and so that they may at times share their favorite activities. Suggest that the advocates encourage the protege to help in making decisions about what to do. The advocate should also observe to learn what the protege enjoys doing most. Make suggestions of things to do.

Behavior

Encourage citizen advocates to treat their proteges like any other friends, to introduce them as such, and to share other friends with them.

Stress that citizen advocates are friends, not social workers, maids or chauffeurs. Advocates must learn to say "no" to teachers, social workers, families, etc., who want citizen advocates to fulfill their roles for them.

Advise citizen advocates to give their proteges a chance; to support them as they take occasional, normal risks, and to help them accept challenges. Citizen advocates should encourage their proteges to TALK to them.

Working With the Family

Discuss the importance of citizen advocates making every attempt to become and remain the friends of their proteges' families, if they are in any way involved in their lives. Ask that, if citizen advocates experience any difficulty in this area, they notify the coordinator immediately.

Citizen advocates must remember that their primary responsibility is to their proteges. Should a family be experiencing extensive unmet needs, the advocate should relay problems to the Citizen Advocacy coordinator for referral to appropriate agencies.

Working with Professionals

Advocates should become acquainted with professionals who are involved with their proteges. They should maintain on-going contacts in order to determine the status of their proteges in their activities and programs (e.g., educational or vocational). Advocates should also be available to professionals to provide valuable feedback and guidance. A courteous and cooperative relationship between advocates and professionals should be maintained.

Expectations

Citizen advocates should never underestimate their pro-

teges; they may be amazed at their friends' undeveloped potentials and by what they CAN do. However, they cannot "cure" their proteges. They also cannot change their life-styles as much as they might want to: THEY SHOULD NOT IMPOSE THEIR PERSONAL VALUES UPON THEIR PROTEGES. (Cite instances where they should be concerned, as in drug abuse, criminal behavior, etc.) Citizen advocates should not expect too much too quickly in terms of "rewards". Their proteges may require a long time to develop trust, affection, interest and concern.

Confidentiality

Citizen advocates should treat all personal information they receive from the coordinator or professionals working directly with their proteges as strictly confidential.

However, information they receive from their proteges is not privileged. If they possess information regarding their proteges' involvement in a criminal act, they may have to testify against them in court.

Rights (see Book III, pp. 27-28)

The proteges' rights extend to legal, social, educational, employment, and general spheres.

What Citizen Advocates Can Do If They Feel These Rights Are Jeopardized (see Book III, pp. 29-30):

1) Observe and document the situation;

2) Contact the coordinator and keep the Citizen Advocacy Office informed at all stages of procedure. Work with the Citizen Advocacy

coordinator to develop strategies.

3) Possible strategies determined by the advocate and coordinator might be to:

   a) Contact the person immediately responsible, then the supervisor if necessary;

   b) If satisfaction is not obtained, contact the key offices, agencies and boards with an action plan to remedy the situation;

   c) If there is agreement for changing the situation, monitor to see that there is follow through; and

   d) If the citizen advocates are not successful to this point, they can work with the Citizen Advocacy Office to utilize alternate methods (publicity, legal action).

Examples of Advocacy in Action

INSTRUCTIONS FOR PREPARATION OF CARDS FOR THE "EXAMPLES OF ADVOCACY IN ACTION" EXERCISE:

Prior to the training session, type up 3"X5" index cards bearing the information related under the Situation sections in the following exercise. Prepare them so that they contain only one situation per card and are numbered according to the sequence given below. For example, Card #1 would read:

"CARD #1

Tommy bought over $50.00 worth of books from a door-to-door salesman. Tommy, who is mentally retarded, cannot speak or read, so the advocate surmised that he did not know what he was buying. Tommy had put $30.00 down and still owed the balance. What should the advocate do?"

The Possible steps in solving the problem and the Actual solution sections of the exercise should not be included on the card. Make a sufficient number of sets of cards (perhaps ten) so that each advocate may use one of a complete series of cards #1 and #2. These cards may be returned to the instructor at the end of the exercise and used again for training.

1) Situation: Tommy bought over $50.00 worth of books from a door-to-door salesman. Tommy, who is mentally retarded, cannot speak or read, so the advocate surmised that he did not know what he was buying. Tommy had put $30.00 down and still owed the balance. What should the advocate do?

Possible steps in solving the problem:
a) Communicate with Tommy as to whether or not he wanted the books;
b) Contact the Citizen Advocacy Office to seek advice;
c) Write the company involved;
d) If the company fails to respond in a positive manner, obtain a legal opinion (legal aid, resource committee lawyer);
e) Take the matter to small claims court, if necessary.

Actual solution: The advocate wrote the company several letters and Tommy received his deposit in the mail.

2) Situation: Timothy lived in a "boarding school" dormitory, and complained to his advocate that the housemother beat the children. The advocate called the Citizen Advocacy coordinator who advised him to contact the school's social worker, which he did. The social worker claimed Timothy was making up stories in the hopes of moving away from the residence. This situation repeated itself, and then Timothy himself appeared with bruises, claiming that the housemother had beaten him. What should the advocate do?

Possible steps in solving the problem:
a) Contact the Citizen Advocacy office;
b) Contact the social worker;
c) Contact the school's administrator;
d) Have the Citizen Advocacy Office's resource committee lawyer write a letter to the school;
e) Have all parties agree to conduct an investigation;
f) Report the offense to the agency which licenses the facility;
g) Take legal action or publicize the event in the news media.

Actual Solution: The advocate and the school administrator agreed to a compromise. The housemother would receive intensive training in constructive behavior modification techniques. If the incident recurred, the housemother would be dismissed. The advocate continued to monitor the situation.

PART III: COMMUNITY RESOURCES

Steps For The Instructor:

step one - discuss the purposes of the activity by referring to the objectives under this section, PART III: COMMUNITY RESOURCES.

step two - conduct the activity according to the outline provided on pages 87 and 88.

step three - conduct the "Exercise in Wending Your Way Through the Bureaucratic Maze" by handing out typed cards A, B, and C to each of the advocates at the training session. Read and discuss each card in sequence given on page 88. (Instructions for the preparation of these cards are included in the text on pages 88-89.)

step four - answer questions concerning the material covered in the COMMUNITY RESOURCES section.

OBJECTIVES FOR PART III: COMMUNITY RESOURCES

The purposes of this activity are to:

1) Identify for citizen advocates those agencies responsible for providing services to their proteges.
2) Point out to advocates the gaps in community services for mentally retarded citizens which the ARC has identified.

AN OVERVIEW OF LOCAL PROGRAMS AND SERVICES

The content of this section will vary greatly from community to community. The coordinator may elect to use an already constructed large chart showing the various facilities and how they relate to state and local government agencies.

The survey of community resources will be very important for the citizen advocate as this identifies agencies with which the advocate may very well have to deal. Be sure the overview covers administrative agency and funding mechanisms of the following services:

- day training
- respite care
- education (public and private)
- foster placement
- institutions
- other residential facilities
- sheltered workshops

- recreation programs
- employment opportunities
- welfare department
- SSI benefits

Exercise in Wending Your Way Through the Bureaucratic Maze

INSTRUCTIONS FOR PREPARATION OF CARDS FOR THE "EXERCISE IN WENDING YOUR WAY THROUGH THE BUREAUCRATIC MAZE"

Prior to the training session, type up 3"x5" index cards bearing the information related under sections a, b, and c below. Prepare the cards so that they contain only one situation per card and are lettered according to the sequence given below. For example, Card A would read:

"CARD A

A seven-year old mentally retarded girl is physically abused in her home. What steps might be taken, and to which agencies would you go, to alleviate the situation?"

Make a sufficient number of sets of cards (perhaps ten) so that each advocate may use one of a complete series of cards A through G. These cards should be returned to the instructor at the end of the exercise and used again in future training sessions.

a) A seven-year old mentally retarded girl is physically abused in her home. What steps might be taken, and to which agencies would you go, to alleviate the situation?

b) A twenty-four year old man who is mentally retarded lives at home with his parents. His siblings are grown and gone. He has no activities other than helping around the house and watching TV. What steps might be taken, and to which agencies would you go, to help him towards a more active, independent life?

c) A forty-five year old mentally retarded man is destitute and staying in a crisis shelter. What steps might be taken, and to which agencies would you go, to help him get food, shelter, money, and eventually a home and a job?

PART IV: RESOURCE MATERIALS FOR THE CITIZEN ADVOCATE

Steps For The Instructor:

step one - discuss the purposes of the activity by referring to the objectives under this section, PART IV: RESOURCE MATERIALS FOR THE CITIZEN ADVOCATE.

step two - pass out your program's orientation kit to each of the advocates. Give them a moment to review its contents.

step three - answer any questions the advocate may have concerning the materials covered in the entire second training session.

OBJECTIVES FOR PART IV: RESOURCE MATERIALS FOR THE CITIZEN ADVOCATE

The purposes of this activity are to:

1) Provide the citizen advocate with in-depth written materials for self-initiated study.
2) Give the advocate handy reference materials for future use.

ORIENTATION KIT

Give a brief description of the contents of the materials and encourage the citizen advocates to read everything very carefully at a later time.

Suggested Materials for Orientation Kit:

- Avenues To Change, Books I & III, if not previously provided
- Dehumanization vs. Dignity (NARC pamphlet)
- The Dignity of Risk (NARC booklet)
- How the Child Develops Intellectually (NARC booklet)
- Facts on Mental Retardation (NARC pamphlet)
- Local and state ARC Annual Reports
- Into the Light of Learning (NARC pamphlet)
- "Declaration of General and Special Rights of the Mentally Retarded" (International League of Societies for the Mentally Handicapped - available from NARC)
- Publicity release (to be signed by the advocate, giving the Citizen Advocacy office permission to use his or her name and photograph for promoting the program) An example

of this release form is in Book II, p. 31.

- Information on tax deductions for volunteers
- ARC membership application form
- Supply of monthly activity report forms (An example of this form is in Book II, pp. 54-55.)
- Information on the NARC Child Advocacy Project
- A bibliography of resource materials.

SECTION III

TOPICS FOR IN-SERVICE TRAINING

MONTHLY IN-SERVICE TRAINING SESSIONS FOR ADVOCATES

Guidelines for Conducting Monthly Sessions

Brief monthly training sessions should be provided for citizen advocates. Allot approximately thirty minutes to a program of interest to as many advocates as possible. All advocates can benefit from meetings and should be encouraged to attend.

Allow the advocates to have a rap session, preferably in a comfortable environment, for another hour to hour-and-a-half during which they may share experiences with one another and ask each other's advice on how to handle certain situations. They can also help the coordinator determine what programs will be of interest at future meetings.

In order to maximize the effects of training, the advocates may be encouraged to engage in a "phone pool" where they share telephone numbers and can contact other advocates whom they respect and/or who share a similar type of relationship. The advocates can seek advice or feedback on ideas on an as-needed basis.

SOME SUGGESTED TOPICS FOR THE MONTHLY MEETINGS

OBJECTIVES:

The purposes of this program are to:

1) Give new citizen advocates the first-hand experience of sharing with people who have been involved with the program for some time.
2) Help new advocates understand the uniqueness of the relationship between the advocate and protege

Panel of Advocates and Proteges

A panel of at least four persons (advocates, proteges and parents) should participate, with the coordinator acting as moderator. If two relationships are featured, they should be of contrasting nature, varied by protege's age, residential setting, functional level, race, sex or basic lifestyle.

Suggested Approach:

This should be a small, informal, non-threatening group. Everyone on the panel will be well-acquainted with the coordinator. These factors should combine to make even shy, self-conscious people feel relatively comfortable. The ambiance should be as casual as possible.

Participants should be invited to speak for about five minutes concerning the nature of their relationship, how they feel about one another, and what kinds of activities they share. If the citizen advocate has performed an instrumental role as mediator between the family and a service agency, or

has "confronted the establishment" on behalf of the protege in any way, the advocate should be invited to speak to this. If parents are participating, they should be invited to speak about any hesitation or confusion they initially experienced over Citizen Advocacy, and tell what the advocate did to gain trust and confidence.

Allow five to ten minutes for questions from the audience of citizen advocates.

CURRENT TRENDS IN LEGISLATION/LITIGATION

OBJECTIVES:

The purposes of this program are to:

1) Raise the citizen advocates' consciousness of legal and human rights.
2) Advise the advocates of legislation which affects mentally retarded people.
3) Inform citizen advocates about current national trends regarding laws which affect the handicapped.
4) Acquaint citizen advocates with resources concerning law and the handicapped.

Suggested Approach:

The area of law and the handicapped is in constant flux and this guide can do no more than suggest areas which should be covered and cite sources for keeping up-to-date on new legislation and litigation. Preferably, there will be an authority on this subject in your community who is available

to you (possibly from your Advisory or Resource Committee) either as a speaker or as a resource person to brief you on important issues. Sources of information might include:

Newsline - the newsletter of the National Center for Law and the Handicapped, 1235 North Eddy, South Bend, Indiana 46617.

Government Report, Outlook in Washington, and Action Alert - publications of NARC's Governmental Affairs Office, Suite 516, 1522 K Street, N.W., Washington, D.C. 20005.

Word From Washington - United Cerebral Palsy Association's legislative newsletter

The Mental Health Law Project Summary of Activities-The Mental Health Law Project, 1751 N Street, N.W., Washington, D.C. 20036.

State Governmental Affairs Chairperson

ARC Executive Director

ARC Local President

Local ARC Governmental Affairs Chairperson

The primary area of interest for citizen advocates will be their local community, but they may very well develop an interest in the larger legal scope. At any rate, they will benefit from a sound background in major current thrusts of the laws affecting handicapped persons.

Important content areas for a discussion on rights would include:

- Background of the civil rights movement;
- The International League of Societies for the

Mentally Handicapped's "Declaration of General and Special Rights"

- Federal Legislation
- Litigation: Precedent setting cases relating to right to education (Pennsylvania Association for Retarded Children v. Commonwealth of Pennsylvania); right to treatment (Wyatt v. Stickney); and right to just compensation (Brennan v. Sauder)
- State and local legislation and litigation

RESIDENTIAL SERVICE ALTERNATIVES

OBJECTIVES:

The purposes of this program are to:

1) Acquaint the citizen advocate with the variety of residential service alternatives available to mentally retarded children and adults.
2) Identify residential service alternatives in relationship to the normalization principle.
3) Help citizen advocates evaluate their protege's residential setting.

REFERENCES

Residential Programming for Mentally Retarded Persons, Books I-IV, NARC, 1972.

Observing in Institutions, Robert Bogdan, Human Policy Press, P. O. Box 127, University Station, Syracuse, N.Y., 13210.

The Right to Choose, NARC, 1973.

Suggested Approach:

Identify residential services in your community according to the following alternatives:

- Multi-purpose large institution
- Small institutional setting within the community
- Boarding homes
- Nursing homes
- Small group homes
  - -Maintenance of life
  - -Infant nursery
  - -Child Development
  - -Pre-vocational
  - -Habit shaping
  - -Structured correctional
  - -Training hostel
  - -Sheltered living
  - -Minimal supervision
  - -Crisis assistance
  - -Five-day residence
- Co-resident apartments
- Foster home
- Natural/adoptive home
- Independent living

Suggested resource films:

"Merging Right" - 30 minutes, color/sound 16mm
Colorado Department of Institutions
Division of Developmental Disabilities
306 State Services Building
Denver, Colorado 80203

"They're Coming Home" - 27 minutes, color/sound 16mm
Pennsylvania ARC
1500 North Second Street
Harrisburg, Pennsylvania 17102

"Where Do They Go From Here?") slide presentations
) available from NARC
"Are They Happy?") Regional Offices

POVERTY AND MENTAL RETARDATION

OBJECTIVES:

The purposes of this program are to:

1) Inform the advocates of the relationship between poverty and mental retardation.
2) Help the advocates understand the special problems of low-income mentally retarded persons and their families.
3) Assist the advocate in developing successful relationships with low-income families.

REFERENCES

Plan For Everyone: The Involvement of Low-income and Minority Members, NARC, 1973.

The Six-Hour Retarded Child, PCMR, 1970.

Suggested Approach:

This presentation might best be handled by one or more speakers who either work on a daily basis with low-income and minority groups or who are themselves representatives of these populations. For instance, you may wish to invite the director or a worker from a diagnostic and evaluation clinic or an outreach program to discuss the relationship between poverty and mental retardation, and a representative of an action center,

crisis center, or neighborhood health center to discuss the "do's" and "don't's" of interacting with low-income people. One person may be able to discuss both topics adequately, but it is important that he or she be knowledgeable in both areas.

Since the physical influences of poverty were discussed in the First Training Session, this discussion should focus on the cultural aspects of poverty and their relationship to mental retardation. Specific topics to discuss might include:

- What are the social and economic characteristics of low-income areas?
- What are the general problems faced by people who live in low-income areas? (e.g., a family struggling to survive as a unit may not be able to channel adequate attention towards a high-risk family member; a single parent working to support children may not be able to provide intensive care to newborns; and the insular nature of communities which are both ethnic and low-income may shield mothers from information on child-rearing techniques.)
- Does the dominant culture impact upon the labeling of children as being mentally retarded? (Many children who function normally within their home environment are placed into special education classes at school. This is particularly true of children who speak a second language.)

This discussion might also touch on the following problem areas:

- Generally poor health care, especially with regard to information on proper nutrition;
- Isolation from services;
- Mistrust of service workers; and
- The cyclical nature of poverty

In relating to ethnic or low-income families, the advocates should:

- Be aware of negative expectations of low-income and/or minority groups in relation to middle-class workers in their communities and what types of experiences these attitudes (stereotypes) are based upon.
- Approach people with a desire to learn from them what their needs and concerns are. Listen with respect to what they have to say. Distinguish between what they need and what you think they ought to have.
- Become acquainted with the resources available in their neighborhoods and with their friends and neighbors.
- Prove that you can be trusted.
- Recognize that the goal of helping people to help themselves is especially important in relating to low-income families. You are there to help, not to give.
- Inform your protege's family about the ARC. Accompany them to an ARC meeting and introduce them to other members.

OTHER SUGGESTED TOPIC AREAS

- Seizure control
- Multiple handicaps
- Sex education
- Emotional disturbance
- Infant Development
- Supplemental Security Income
- Voting
- Panel on employment
- Food stamp program
- Behavior modification
- Workshops, pre-schools, institutions, recreation programs and other direct services.

SECTION IV

APPENDIX AND BIBLIOGRAPHY

APPENDIX A

APPENDIX A

The following lecture outline is provided for an alternative presentation to the slide show, "History of Mental Retardation", in Part III: HISTORY OF ATTITUDES AND PRACTICES CONCERNING MENTALLY RETARDED PERSONS, pp. 22-43.

Historical Overview of Mental Retardation

Primitive Societies: Aboriginal mankind, up through the early Greek civilization, left all deviant newborns to die of exposure. The struggle for survival among these early peoples did not allow enough surplus resources to support dependent members of society.

Greek and Roman Civilizations: More sophisticated civilizations reflected an atmosphere of curiosity about the disabled. The Greeks believed that persons with epilepsy spoke to the gods during their seizures and consequently treated them with honor and respect. Roman intellectuals experimented in training efforts with those whom they referred to as "feeble-minded".

Middle Ages: In addition to the difficult hand-to-mouth existence which prevailed, unenlightened attitudes made life extremely hard for handicapped people. A few were kept by wealthy households as jesters who provided entertainment; some were sheltered in convents or monasteries as children of God; others were left to beg in the streets. Those who were fortunate enough to have "hidden" handicaps, such as mild mental retardation, could blend into the mainstream of society.

Renaissance Period: As powerful kings carved Europe into nations, their magnificent palaces housed collections of human oddities as entertainers and objects of fascination.

Reformation (15th Century): Martin Luther referred to the deviants of society (which included mentally retarded people) as "soulless creatures" who were "filled with Satan". His attitudes were reflective of the popular belief in the supernatural at work in making people handicapped.

17th Century America: The Roman Catholic settlers in the South tended to have a disinterested attitude towards the handicapped. The rigid conformity of the Puritans in the northern settlements, however, inspired violent retribution towards deviant members of their culture. Considered either witches or evidence of a witch's evil influence, numerous mentally retarded citizens were burned at the stake.

18th Century Europe: The counter-Reformation, imposing rigid rules of belief and behavior, affected the lives of mentally retarded persons whose behavior made them noticeable non-conformists. A lengthy era of institutionalizing all deviants in one facility began. A noted example of this practice was Bethlehem Hospital, or "Bedlam" as it was popularly known, in England. Retarded and insane persons existed here together, and wealthy citizens paid admission fees to tour the asylum and watch the antics of the "mad" folk.

19th Century France: A physician named Itard conducted a training program with a wild boy, or ferral, named Victor. The records of his experiments inspired an admirer, Seguin, to begin schools for "curing" what was then called "idiocy". Seguin emigrated to America and initiated his programs here.

1880-1900: What began as an attempt to help mentally retarded people became an effort to protect society from them. The small schools envisioned by Seguin evolved into vast warehouses behind locked fences.

1900-1950: Training programs were gradually replaced by custodial care. Routines were established for the convenience of the staff at these institutions so that they could handle large numbers of residents at one time. Because there were no services available to mentally retarded people in the community, these people were congregated into huge groups, segregated from society and from the opposite sex.

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At the end of this presentation, turn back to page 44 of the guide and continue to lecture according to the outline given there, beginning with the section labeled "Common Models".

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"Graduation", James S. Stanfield, Ed.D., 5151 State University Dr., Los Angeles, California 90032. Color/sound, 16mm.

"Normalization", Atlanta ARC, 1687 Tulley Circle, N.E., Suite 110, Atlanta, Georgia 30329. Color/sound, 16mm.

"When May Comes We'll Move to the First Floor", United Cerebral Palsy Association.